



پاکستانی سیلیک سوسائٹی
Pakistani Celiac Society
www.celiac.com.pk

گلوٹن کے بغیر روزمرہ زندگی All About Gluten-Free Lifestyle

NEWSLETTER

Winter 2010

DIRECTORS

President--Mr. Ahsan Rashid
General Secretary -- Mr. Sultan Yousaf
Treasurer -- Mrs. Maria Avais

Founder & Patron:

Dr. Mohsin Rashid FRCP(C)
Paediatric Gastroenterologist

MISSION STATEMENT

The Pakistani Celiac Society is a national, volunteer, non-profit organization dedicated to provide support and services to individuals and families with celiac disease and dermatitis herpetiformis through programmes of awareness, advocacy and education.

What is New?

Report on the inaugural Meeting 06, March 2010

The inaugural meeting of the Pakistani Celiac Society (PCS) was held in the evening on Saturday 06, March 2010 at the Royal Palm Golf and Country Club, Lahore, Pakistan.

The meeting was attended by patients and parents of children with celiac disease, physicians, medical students, representative from the food industry, television media personnel and members of general public.

Mr. Ahsan Rashid, President of the PCS opened the proceedings by welcoming the guests and describing the objective of the meeting. The purpose of the meeting was to increase awareness of celiac disease and provide an opportunity for patients and families to meet each other and share ideas and information about the disorder and gluten-free diet.

Dr. Mohsin Rashid gave a presentation entitled "**Celiac Disease in Pakistan: Awareness and Patient Support**". This was a detailed presentation in Urdu on various aspects of celiac disease. The history behind the creation of the Pakistani Celiac Society was described.

The development of the web site has been the first step in accomplishing this mission. Today's inaugural Meeting is a landmark in the history of PCS, as the organization has now become a reality and it is hoped that it will grow over time. Increasing the membership is essential to the growth of the organization and all present were asked to encourage others to join the free membership by completing the on-line registration form.

The pathogenesis, clinical features and diagnostic issues in celiac disease were highlighted in the presentation. Availability of gluten-free foods in Pakistan is very limited and work needs to be done in this area. The scope of celiac disease in the country is not known and should be investigated.

The web site of PCS has been active. It is being regularly updated to provide current information. A live demonstration of the web site was also undertaken to show various features. Printable brochures are available on the website. Gluten-free recipes are being added.

The first quarterly Newsletter of PCS was created and emailed to all members in the fall of 2009. The Newsletter will be further improved. A Board of Directors has been assembled who will provide leadership to carry the organization forward in the future. Medical Advisors, both local and international will help provide guidance on various scientific aspects of celiac disease and gluten-free diet. This

list is being expanded as more health professionals with an interest in this area are being contacted.

Dr. Rashid stated that the future challenges and opportunities include continuing patient information and education and promoting advocacy by improving awareness of celiac disease amongst the health professionals, food industry and society in general. Collaboration with regional celiac support organizations would be helpful for sharing common information. The essence of all these efforts is to improve availability of affordable gluten-free products and make life a little easier for patients with celiac disease in Pakistan.

A special thanks was given to Mr. Ahsan Rashid for help in arranging the venue of the Meeting, Mr. Kashif Jilani of Softmatics™ for support with the original design and hosting of the present web site, Mr. Sami Ullah, Manager of Future Vision Technologies™ for developing the current web site and to Mr. Suleman Sheikh of ColorMath™ for help in printing the banners and posters. Dr. Rashid also acknowledged the huge and tireless efforts of Sultan Yousaf in moving the PCS project forward.



Dr. Rashid giving presentation

Mr. Sultan Yousaf, General Secretary PCS, gave a presentation on “**Challenges of Gluten-free Diet**”. He highlighted the importance of reading labels when buying food products to ensure that they are gluten-free. It was stressed that label reading is an important concept to understand and practice. The individuals should learn to read the labels carefully not only themselves but also train their children to do so. Examples of good and poor labeling were provided. Labeling can be deceptive when enough information is not listed or is distorted. No matter what the product label says, a food product that is made from or contains any amount of wheat, barley or rye is not gluten-free and should not be consumed. The PCS will provide regular updates on new products and alerts on deceptive labeling.

The presentations were followed by a question and answer session. The participants showed a keen interest and appreciation in the efforts of PCS and the potential benefits it may have for the patients.

Currently, the main source of disseminating information and communication is through the web site. A concern was

raised that many individuals in Pakistan do not have access to internet and hence other means of distributing information should also be considered. This could include sending printed brochures to smaller district hospitals and making oral presentations in those centers.

Gluten-free foods imported from other countries are very expensive. Efforts must be made in getting the food producers and suppliers to create gluten-free foods from locally available ingredients.

The PCS is working on several initiatives. There is a plan to hold a cross country tour which will include a series of lectures on celiac disease at various medical institutions. There will also be collaboration with the Pakistan Society of Gastroenterology and GI Endoscopy where a joint seminar on celiac disease is being considered. This will provide a means of promoting awareness of celiac disease amongst the medical professionals.

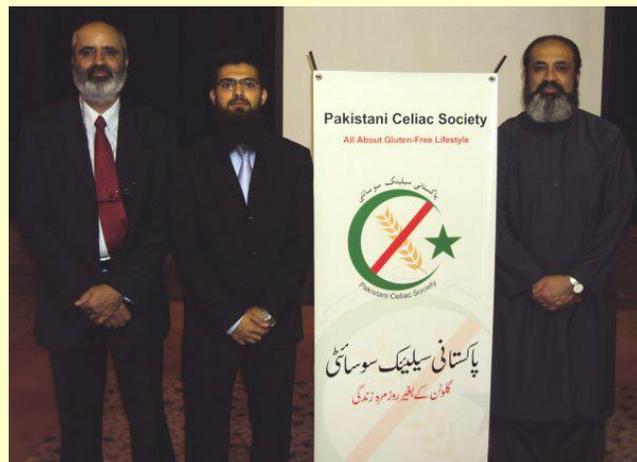
Display banners listing common symptoms and signs of celiac disease are being printed which will be exhibited at various meetings and conferences.

The PCS hopes to compile a Food and Drug directory and provide it free both in Urdu and English. Currently, printable restaurant cards for members are available only from the web site. These will be developed in a laminated format and distributed to members.

After the formal presentations, the participants had an opportunity to meet each other and discuss issues of mutual interest. A souvenir key ring of the PCS was presented to all the guests at the Meeting.

It is hoped that similar meetings will be held regularly in Lahore and in other major cities across the country.

The Meeting concluded with a gluten-free dinner.



From Left: Ahsan Rashid, Sultan Yousaf, Dr. Mohsin Rashid

Visit our Web Site
www.celiac.com.pk

Cure for Celiac Disease?

A strict gluten-free diet can be challenging. Reading labels and worrying about contamination becomes part of life for those following this diet. Individuals with celiac disease can sometimes get frustrated with following a gluten-free diet and wonder whether this problem can be cured.

There is exciting research going on around the world to investigate how a permanent cure for celiac disease can be achieved.

Stay tuned for more information on this topic in the upcoming Issues of the Newsletter.

Recipe of the Month



CHOCOLATE CAKE

Ingredients:

- 1). Corn flour 1 cup
- 2). Rice flour 1 cup
- 3). Cocoa powder 3/4 cup
- 4). Baking powder 2 teaspoons
- 5). Baking soda 1 teaspoon

Recommended: Rossmoor or any one made from maize starch

- 6). Oil 1/2 cup
- 7). Eggs 2
- 8). Sugar 1/2 cup
- 9). Cooking chocolate 4 oz

Preparation:

- Mix corn, rice flour, sugar and baking powder and soda in a large bowl
- Add coco powder
- Separate egg whites from the yolks. Add yolks to the mixture, beat egg whites separately till it converts into white foam
- Now add egg whites and blend well with the mixture, add oil in the end
- The mixture should not be too thick or too liquid
- Grease a round or square shaped baking dish with butter and pour the mixture gently.
- Bake the mixture on P HI for 4 minutes in microwave.
- Melt cooking chocolate on low heat and spread it on top of the cake.

ENJOY!

Diagnosing Celiac Disease

Celiac disease is a common problem. Typical symptoms of celiac disease include abdominal pain, diarrhea and weight loss. However, many individuals present with atypical symptoms including anemia, fatigue, mouth ulcers, short stature, bone pain, menstrual irregularities and infertility. In children delayed growth and puberty, vomiting and irritability can also occur. Celiac disease is a hereditary disorder. Both first and second-degree relatives are at risk of developing celiac disease. Other high-risk groups include individuals with other autoimmune disorders like type I diabetes (insulin-dependent) and thyroid disease.

If you suspect that you or your family member may have celiac disease, the following steps are recommended:

- (1). Consult with your doctor.
- (2). Serological (blood) testing with IgA tissue-transglutaminase (TTG) antibody is recommended for screening. This test is commonly referred to as TTG and is now available in Pakistan in selected hospitals.
- (3). The definitive test to confirm celiac disease is a biopsy of the small intestine. This is obtained by endoscopy.
- (4). Do NOT start a gluten-free diet before confirmation of the diagnosis.

The treatment of celiac disease is a strict gluten-free diet for life. The gluten-free diet should not be started before a biopsy is done, as it will affect the interpretation of the biopsy and make confirmation of the diagnosis difficult.

Gluten-free Flours

Daali Earth Foods have marked gluten-free flours in various grocery stores across the country. Their gluten-free range includes: *bajra* flour, *baisan* (chickpea flour) and organic brown rice flour.

It is the manufacturer's responsibility to ensure that gluten-free products marketed are not in any way derived from wheat, barley or rye and contamination with these gluten-containing grains is strictly avoided in the preparation of such gluten-free products. The food products should be adequately tested to meet the standard of being gluten-free. While the Pakistani Celiac Society has no means of verifying the gluten-free status of any food product marketed in the country, we invite the members to try these products by Daali Earth Foods and visit their web site at www.daaliearthfoods.com for more information.

Joining Hands



Membership of Pakistani Celiac Society is Open to All

Join our free membership on-line at

www.celiac.com.pk

Contact us at info@celiac.com.pk